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Community Health Worker-Led Community Clinical on the U.S. / Mexico Border: Lessons Learned

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Abstract

Background: Community-Clinical Linkages (CCLs) connect public health organizations and healthcare providers to better support patients. Community Health Workers (CHWs), representatives from priority populations with special connections to their community, can lead CCLs.

Objectives: Our objective was to learn about how to conduct a CHW-led CCL from the perspectives of those implementing the intervention.

Methods: We conducted focus groups with CHWs and their supervisors and regularly consulted community partners while coding and analyzing data.

Results: We learned that CHWs thrive when supported by peers, supervisors, institutions, and researchers. Supervisors - who are new to the CHW role - should consider seeking training in CHW professional development and performance evaluation. Focus group participants agreed that by balancing the strengths and weaknesses of their organization, CHW-led CCLs benefit patients because the collaboration helps them to better manage their health.

Conclusions: Future CHW-led CCL practitioners should consider how to best institutionally support CHWs to maximize benefits for patients.

Keywords

Community Health Worker; Community Clinical Linkage; Chronic Disease Self-management

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Background

Community Clinical Linkages (CCLs), or 'mechanisms for linking patients to community resources…[with] the assurance that the resources referred to have been accessed,"[1] can have positive health benefits for patients.[2] The Agency for Healthcare Research and Quality states that CCLs, "help to connect health care providers, community organizations, and public health agencies so they can improve patients' access to preventive and chronic care services."[3] As frontline public health workers with a special connection to their community, community health workers (CHWs) are ideally positioned to build CCLs. They link community members to health and social services thereby improving the responsiveness of the services offered through support and navigation as well as increasing self-sufficiency in the community.[4] Apart from Stupplebeen et al. (2019), little research exists about the implementation of CHW-led CCLs from the perspectives of CHWs and their supervisors.[5]

In this paper, we aim to fill this gap by describing a long-standing community-academic partnership at the Arizona Prevention Research Center (AzPRC) which is intended to address chronic disease prevention and management among the Latinx population living on the U.S. / Mexico border. We present data from focus groups with research partners that address lessons learned from the CHW-led CCL we developed in a three-year prospective matched observational study entitled *Linking Individual Needs to Community and Clinical Services* (LINKS).[6]

Objectives

Our objective in holding focus groups with the LINKS CHWs and their supervisors was to engage partners in an exploration about how best to conduct a CHW-led CCL. This information will be used to improve our future CHW-led CCL interventions and inform other researchers and public health professionals.

Context of Community Partnership

The AzPRC commitment to addressing health disparities in border communities is rooted in partnerships with the Community Action Board (CAB) members that originated 25 years ago, with most organizations from the original partnership still reflected today in membership. The CAB provides guidance in all aspects of the AzPRC. As a partnership, we strive for shared leadership that is grounded in a high level of communication, exchange, and trust.[7] CAB members include 20 representatives from health departments, federally qualified health centers, area health education centers, and community-based organizations from Yuma, Pima, Cochise, Santa Cruz, and Maricopa counties, as well as representatives from the Arizona Department of Health Services chronic disease programs. For the LINKS study, we worked together toward a common research goal by co-creating our collaborative activities.

Methods

The LINKS intervention is a CHW-led CCL that was developed by members of the CAB research committee and implemented in three U.S.-Mexico border counties: Pima,

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Yuma, and Santa Cruz. In each site, one CHW at the county health department (community-based CHWs) and one CHW at a federally-qualified health center (clinic-based CHWs) collaborated to tailor the intervention to their local context (six CHWs total). Clinic-based CHWs referred adults with a diagnosed chronic disease or pre-chronic disease (such as pre-diabetes) to the community-based CHW. The community-based CHWs also recruited individuals who met this inclusion criteria from the clinic waiting room, community events (such as health fairs), and existing groups (such as regular church meetings). The community-based CHWs then met with participants monthly for six months (although they had the opportunity to communicate more frequently during and after the intervention ended if needed). The baseline meeting was conducted in-person while the follow-ups were held either in-person or over the phone per the participant's preferences.

LINKS community-based CHWs had four roles. First, the community-based CHWs administered an emotional wellness survey during the baseline, three, and six-month visits. Second, they assessed the participant's social determinant of health needs, identified appropriate resources, and referred them to any needed services to address issues such as food insecurity. The CHWs developed lists of existing resources which they regularly updated. It is important to note that more resources were available in the urban site (Tucson, Arizona) versus the rural sites (Yuma and Nogales, Arizona). Third, the community-based CHW offered the participant referrals to health promotion activities such as chronic disease education and physical activity classes. Fourth, in the event that the participant had medical needs, the community-based CHW communicated with the clinic-based CHW to help the participant access health and behavioral health services. The intervention was participant-driven. Beyond the emotional well-being survey, the participants determined the place, content, and time needed with the CHWs. Additionally, the CHWs made sure to follow up on all referrals and invited participants to contact them after the intervention ended to ensure participants received all needed assistance. The CHWs communicated using Research Electronic Data Capture (REDCap)[8, 9] messenger – a Health Insurance Portability and Accountability Act (HIPAA) compliant communication tool within our LINKS REDCap database. They also met monthly for a CHW peer network meeting where they celebrated successes and discussed challenges as a group. We provide further details on LINKS in a paper about the study protocol.[6] The focus groups we describe in this article were a part of the LINKS study.

Positionality of Researchers

An interdisciplinary team of researchers - including the first, third, and last authors - collected data. We are part of a larger research team made up of Latinx, multi-racial, and White faculty, staff, graduate students, and CAB members either employed by a university or by a public health agency located in the Southwest United States. All team members have experience and knowledge about the Latinx community and all participate in a collaborative effort to improve the public health issues that affect Southwest communities. Four CAB members are co-authors on this article (FB, GC, CE, and CD). They contributed their practice-based experience regarding CHW-led CCLs, participated in the focus groups, and gave feedback on manuscript drafts.

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The first and second authors analyzed the data. The first author identifies as White and is a Ph.D. candidate in Public Health. She learned Spanish through coursework, volunteer experience abroad, and employment at a migrant health clinic. She is motivated by a desire to see that immigrant and marginalized communities are able to access healthcare resources. The second author is getting a Ph.D. in Mexican American Studies with a focus on undocumented Mexican immigration to the United States. As the daughter of formerly undocumented immigrants, she is committed to helping marginalized groups and fighting for justice, equity, and human rights.

Feedback on a CHW-led CCL

CAB members and the academic team decided to conduct internal focus groups in order to synthesize lessons learned from implementing a CHW-led CCL across three sites.[10] The research partners developed the discussion questions together which were designed to elicit conversation about the intervention. In conducting focus groups, we sought to cultivate a process of discovery - rather than a sharing of opinions - by engaging CHW and CHW supervisor partners in discussions about their experience implementing the intervention.[11] Because the CHWs and their supervisors are CAB members, and therefore research partners rather than study participants, Institutional Review Board approval was not required for this data collection.

We held the CHW focus group in-person on March 21, 2019. Five CHWs participated. All of the CHWs speak Spanish as a first language therefore we conducted the discussion in that language. We split the CHW supervisor focus group into two parts due to challenges with technology and scheduling conflicts. On February 14, 2019, we conducted the first half of the focus group over Zoom videoconferencing software and then we finished the discussion during an in-person meeting on March 22, 2019. All three CHW supervisors spoke English fluently, consequently the CHW supervisor discussion was conducted in English. Each focus group lasted between two to three hours. We audio-recorded and transcribed all discussions.

Keeping the discussions in their original language, a bilingual qualitative coding team - the first (AL) and the second (SA) authors - analyzed the data. The last author (AWL) provided guidance and oversight as needed. We followed Maguire and Delahunt's six step thematic analysis guide.[12] First, we became familiar with the data by individually reading all the transcripts. Second, we generated initial codes together and coded a small section of each focus group discussion. Afterwards, we compared our coding, reconciled differences, and adjusted the code book accordingly. Next, we individually coded the entire data set using NVivo Software version 12. Third, we identified themes by reading through all the statements captured by one code and searching for significant or interesting overarching ideas that related to our objective of outlining the lessons learned from a CHW-led CCL intervention. Fourth, we reviewed the themes for clarity and ensured that the data supported each theme. Fifth, we defined the themes and clarified the relationships between the themes and subthemes. We regularly engaged our community partners throughout the theme development process to make sure the themes aligned with community member experiences and opinions as well as to guarantee the accurate translation of quotes. Sixth, we wrote up our results.

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Lessons Learned

After analyzing the themes that emerged from the LINKS CHW and CHW supervisor focus groups, we found four overarching areas of interest: support, research, supervision, and outcomes (see Table 1). We further divided the themes into the subthemes of successes and challenges and included the subsequent lessons learned to encourage others to learn from our experiences.

Support.

Through peer network trainings and the use of the REDCap messenger, CHWs learned from each other, built camaraderie, and supported one another when they struggled to use study-related technology. During the focus groups, LINKS CHWs also expressed great admiration and respect for their CCL counterpart (the CHW based in the alternate setting), recognizing their strengths and ability to support participants together. This culture of sharing made CHWs feel empowered by their work and confident that they were helping LINKS participants.

It was difficult for CHWs to provide emotional and social support to participants and themselves due to inherent institutional structures, system protocols, and technological barriers. They found that LINKS participants frequently expressed frustration with providers due to the fast pace of appointments. In contrast, CHWs learned details about participants' lives beyond the routine data collected at provider visits as they gathered additional pertinent information such as social support, and as they spent more time with participants which often included many follow-up calls or visits. As a result, CHWs filled this emotional gap by tailoring their approach to meet the needs identified by the participant. Yet, at an institutional level, CHWs struggled to gain necessary private spaces where they could build a trusting relationship with participants. They also had to regularly change offices and navigate tense interactions with other providers who were not participating in the LINKS study. Additionally, CHWs struggled to create technologically supportive spaces. For example, after recruiting participants at the clinics, community-based CHWs often found that when they called to follow-up from the county health department, LINKS participants would not answer their phones because they did not recognize the number. This problem could have been easily rectified by better alerting LINKS participants that they would be receiving phone messages from the county health department rather than from and the clinic. Overall, CHWs need more support at an institutional level.

CHWs' access and ability to create these nurturing spaces impacted LINKS participants. The CHWs felt that if they could create these private and nurturing physical spaces, it would better enable disclosure of participants' emotions. Through releasing emotional struggles, the CHWs believed LINKS participants could begin to tackle their physical ailments. Yet, this type of community-based work can be stressful and draining for CHWs.[5] In order to keep their passion for the profession, CHWs need to also ensure that they create self-nurturing and peer-nurturing spaces to maintain their work stamina. By taking care of themselves and supporting each other, CHWs are able to work long term. To facilitate the creation of nurturing spaces, future iterations of LINKS should include more frequent CHW

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peer network trainings as well as promote CHW self-care to alleviate burn-out and potential emotional burden.

Research.

Focus group participants appreciated regular support from the academic team which involved providing opportunities for CHWs to tell the stories behind the data at meetings and conferences.[13–15] As a result, both supervisors and CHWs felt empowered as CCL subject matter experts and CHWs had space for self-reflection. Conversely, focus group participants disagreed on whether the LINKS implementation was a success or a challenge. During conversations, there was a push and pull between creating a community-based participatory research (CBPR) project through an iterative process versus having more structure from the beginning. One supervisor embraced the lack of detail and instructions in LINKS and enjoyed the challenge of figuring out how to implement the intervention. In contrast, some CHWs felt there was a lack of communication between themselves and the research team on how to create the CCL as well as what their role entailed. This resulted in challenges associated with research timing. For example, it took longer than expected to establish the CCLs. Moving forward, we imagine this tension will continue as this is part of conducting a study using a CBPR framework. We also acknowledge that it is important to collect and apply all lessons learned to future iterations of LINKS.

An additional research-related challenge occurred when, after a brief training, the academic team assumed the LINKS CHWs had the needed skills to use Ipads and REDCap software. The CHWs found the pressure to use these tools stressful and overwhelming, especially when they were not functioning as expected. Future projects like LINKS should include more technology training for CHWs.

Supervision.

Both CHWs and supervisors said their relationships were positive. They described one-on-one troubleshooting and CCL process discussions as well as professional development - such as providing and seeking CHW training - as helpful. Some CHWs also felt that their supervisor understood their role and was capable of supporting their work. They believed their supervisors provided the emotional support they needed, especially during tough times in the research project. Other CHWs mentioned that it would be beneficial for their supervisors to receive more training on CHW professional development, skills, roles, and performance evaluation.

A key obstacle in LINKS was the absence of clinical CHW supervisors during CCL planning. Due to limited funding and time allocation, the clinical CHW supervisors were not able to participate in the CCL planning. Instead, the funding was primarily assigned to the clinical CHW rather than both the supervisor and CHW. This created logistical barriers such as struggles to establish the CCL recruitment and referral process and misunderstandings about communication between the county health departments and the clinics. As a result, the clinic CHWs had an unsustainable amount of work as they tried to create CCLs without full support from their supervisors. In the future, it is essential to provide appropriate funding for both clinical supervisors and CHWs to be involved in the CCL development process

from the beginning, especially when discussing recruitment and referrals. In this way, clinic CHWs will hopefully have more dedicated time and funding that would be in line with supervisor expectations.

Outcomes.

In the end, focus group participants believed that LINKS, a systems-level CHW-led CCL, benefited participants. Once a CCL was established, they felt that clinic-based and community-based CHWs could balance their personal and institutional strengths and weaknesses through collaboration. For example, in one county, the clinic CHW offered an emotional well-being course while the county health department had a diverse menu of chronic disease management educational opportunities available in a group setting. The CHWs could refer participants to the unique programming offered by each institution. Focus group participants also described how being part of a CCL gave all organizations involved access to more resources. As a result, participants engaged and received the resources they needed and became better managers of their health and social determinant needs. When asked about sustainability, supervisors said this was a challenge and that programs such as LINKS have to be adaptable to be maintained beyond an externally supported funding structure.

Conclusions

By conducting focus groups with CHWs and their supervisors, the AzPRC research team gathered lessons learned from our LINKS research study, a CHW-led CCL. Our findings are similar to those of Stupplebeen et al. (2019) in Hawai'i. Although we conducted our research in different places and contexts, we both found that CHW-led CCLs can successfully support patients with chronic disease. CHWs, however, face challenges including institutional barriers when developing and maintaining CCLs, burnout, and sustainability.[5] This similarity suggests that our results may be generalizable to other contexts.

In the future, we encourage other researchers and community practitioners employing CHW-led CCLs to support CHWs by empowering their voices in research and ensuring they are supported at the institutional level by trained or experienced supervisors. In this way, the CHW-led CCL model can benefit participants by balancing organizational strengths and weaknesses and by providing more access to resources, thus helping participants become self-managers of their chronic disease, mental health, and social determinant needs.[16] Additionally, we encourage health system leaders to leverage the CCL model to strengthen the position of and funding for CHWs so that they can better address issues of healthcare access, quality, cost, disparities, and comprehensive policy and practice changes. Such changes would allow CHWs to contribute fully and effectively to health systems improvements.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Focus Groups with Community Health Workers (CHW) and their Supervisors: Overarching Themes and Lessons Learned

Themes	Examples Given by Participants		Lesson Learned
Support	Success: CHW Peer Support	"la participación de cada una, de cada vez que alguna de ustedes tenía una idea me hacia a mi también implementarla en mi trabajo con mis participantes creo que es como mucho mejor para trabajar en equipo verdad? Que creo que si tenenos éxito a través de saber trabajar en equipo y que podemos…aprendo mucho de todos ustedes." "The participation of each one of us [CHW], of each time that any of you had an idea, it would lead me to implement it as well in my work with my participants. I think it is… much better to work as a team, right? I believe that we do succeed through knowing how to work as a team and that we can … I learn a lot from all of you. " -CHW	**CHWs can balance the strengths and weaknesses of the project through collaboration. CHWs are better able to address challenges through team-based care.**
	Challenge: Creating Nurturing Emotional, Institutional, and Technological Spaces	"la barrera más grande que tuvimos nosotros de compañeras que nos pusieron haz de cuenta en un closet so la habilidad de confianza de que el paciente se sintiera con confianza de pláticas conmigo desaparecio completemante" "The biggest obstacle that we faced, if you can imagine, was when fellow CHWs put us in a closet [sized office] so that the ability to build trust, to have the patient feel at ease to talk to me, completely disappeared"-CHW "Que se está haciendo llamadas [por las Promotoras de salud que trabajan en la comunidad] y el paciente no reconoce el número del teléfono y hay más posibilidad que reconozca el número de la clínica y conteste." "That we [the community-based CHWs] are making calls and the patient does not recognize the phone number so it is more likely that they would recognize the number of the clinic and answer."	**Institutions should provide CHWs with ample private office space and assist CHWs with any technological challenges.**
	Challenge: CHW Self and Peer Nurturing	"Yo puedo ser una madre Teresa de Calcutta le dije si yo quiero le dije pero si yo soy una Community Health Worker, yo tengo que abogar por mis participantes pero si yo no abogo por mi le digo, entonces estoy muy mal y no voy a saber abogar por ellos…tengo que tener algo en mi algo que yo les pueda dar a ellos." "I told her that I can be a Mother Teresa of Calcutta if I want to, but I told her that, as a Community Health Worker, I have to advocate for my participants, but if I do not advocate for myself, I tell her, then I am really in trouble and I will not know how to advocate for them… I have to have something in me, something that I can give to them." - CHW	**CHW supervisors should encourage CHWs to seek peer support and adopt self-care strategies.**
	Challenge: Working with Other Healthcare Providers	"Las enfermeras no nos, nos veían como bichos raros porque no éramos nadie y lo tengo y lo digo por experiencia." "The nurses did not see us, they saw us as strange animals, like we were nobodies. And I know it, and I say it from experience."	**Institutions should encourage health care providers to support CHWs.**
Research	Success: Supportive academic team	"Siente uno bonito que los investigadores estén al pendiente de nosotros… no es nada más que nos llevan y hagan esto y queremos estos resultados, siempre durante todo el programa…los investigadores estarnos dando el seguimiento pues de estar viendo que estaba pasando, como nos podian apoyar o nos daban la oportunidad de compartir entre nosotros las experiencias entonces creo que más para mi fue eso bien importante." "It felt good to know that the researchers were looking after us … they didn't just come to us and say do this, and we want these results, consistently throughout the whole program … the researchers followed-up with us, you know to check on what was happening, to see how they could support us or they would give us the opportunity to share our experiences with one another, so I think that for me that was very important." -CHW	**Researchers should promote and uplift CHW voices at meetings and conferences.**
	Success & Challenge: LINKS implementation	"The fact that when we started the program it was very general, we didn't have a lot of what we will be doing and I think that that panned out along the way which is good, I like that kind of challenge. I thought it was a very good learning experience for me as a supervisor and for program purposes so I don't know that I would see that as a challenge or a barrier. I actually like it." – CHW Supervisor "que manera pueda ser mejor en la siguiente ronda [de LINKS] quizas más claro menos verbish [CHW created word] que no se entiende, más el objetivo que digo más en claro y exactamente que son las responsabilidades de ambos grupos…que fuera más estructurada" "how can the next round [of LINKS] be better, perhaps clearer, with less verbish [CHW created word] that one cannot understand, with more of an objective, I mean, more clarity about what exactly the responsibilities of	**Researchers should continually strive to improve participatory research practices.**

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Themes	Examples Given by Participants		Lesson Learned
		both groups [clinic and county health department] are … that it be more structured"- CHW	
	Challenge: Technology	"Ni siquiera sabia comenzar ni siquiera sabía prenderlo [the IPad for data collection] para mi fue frustrante al principio me sentí presionada porque no sabía que voy hacer aquí…no sabía nada la primera vez que fui con la primera señora" "I didn't even know how to start it or how to turn it on [the IPad for data collection] for me it was frustrating at first. I felt pressured because I didn't know what I'm going to do here…I didn't know anything the first time I went with the first lady [participant]"-CHW	**Researchers should provide regular support to CHWs, especially around technology.**
Supervision	Success: Positive Relationships	"el apoyo [de mi jefa] de que sabes que ahora tengo que ir a la biblioteca, nada ella nada más me decía donde estaba y a no más con eso tenía y sabes que estoy batallando con esto, ok, ven, vamos a juntarnos y vamos a ver entre las dos como lo podemos solucionar entonces siempre hubo mucho, mucha libertad y mucho apoyo" "the support [from my boss] was that now I have to, you know, go to the library, and just like that, she would say just tell me where you are and that's all I needed and you know I would say that I am struggling with this, and she would say ok, come, we are going to get together and we are going to see between the two of us how we can solve it. So there was always a lot, a lot of freedom and a lot of support" -CHW	**CHW supervisors should provide one-on-one troubleshooting support and professional development for CHWs.**
	Challenge: More Supervisor Training Needed	"entrenamiento para el supervisor you know si realmente hace carencias de las habilidades de ser supervisor you know de como se le puede apoyar al supervisor de que aprenda you know de como ser mejor supervisor porque si no, no se va a lograr aha que este fuerte el equipo" "Training for the supervisor, you know, if they are really lacking the skills to be a supervisor, you know, about how they can encourage the supervisor to learn, you know, about how to be a better supervisor because otherwise we will not succeed aha in building a strong team" -CHW	**If new to the CHW role, CHW supervisors should consider participating in trainings in CHW professional development, skills, and performance evaluation.**
	Challenge: Absence of Clinical Supervisors	"I believe the program, the project suffered since from the beginning we didn't have all the stakeholders around the table…not having the supervisors at the clinic hinders so much…it was really challenging not having the supervisors inside the clinic knowing exactly what the CHWs inside the clinic needed to be doing…I don't think it really allowed us to be effective since the beginning." – CHW Supervisor	**All CHW supervisors should be involved in CCL development from the beginning. Additionally, institutions should acknowledge CHWs as integrated members of the institution to ensure seamless interactions between community and clinic-based CHWs.**
Outcomes	Success: Community-Clinical Linkage	"I think this particular program has given them that ability, if they're not already complying…there are people on both sides, on the community side and the clinical side that are not making them responsible but are following-up and offering those resources and that support so I think that for that reason they are being more self-managers, better self-managers." – CHW Supervisor	**As a result of the CHW-led CCLs, participants have access to more resources and become better self-advocates.**
	Challenge: Sustainability	"I think the sustainability makes it a yes and no, we are fortunate enough that the clinic sees these different kinds of things and so that, we could probably keep something like this going. It would be harder to keep it in its pure form but we could use components of it very easily in different programs that we are working on." – CHW Supervisor	**The CHW-led CCL model should be flexible so that it can be applied to a variety of contexts depending on available funding.**

Table 2.

Lessons Learned from a Community Health Worker-Led Community Clinical Linkage

Benefits of CHW-led CCLs

- CHWs can balance strengths and weaknesses of the project through collaboration
  - Capitalize on each other's strengths
  - Better able to address challenges through team-based care
- Participants have access to more resources
- Participants become better self-advocates

Sustainability

- The CHW-led CCL model should be flexible so that it can be applied to a variety of contexts depending on available funding

Support for CHWs

- Researchers should:
  - Provide regular support to CHWs especially around technology
  - Promote and uplift CHW voices at meetings and conferences
  - Continually strive to improve participatory research practices
- CHW Supervisors should:
  - Be involved in CCL development from the beginning
  - Provide one-on-one troubleshooting support and professional development for CHWs
  - If new to the CHW role, consider training in CHW professional development, skills, and performance evaluation
  - Encourage CHWs to seek peer support and practice self-care strategies
- Institutions should:
  - Acknowledge CHWs as integrated members of the institution to ensure seamless interactions between community and clinic-based CHWs
  - Provide CHWs with ample private office space
  - Encourage health care providers to support CHWs
  - Assist CHWs with any technological challenges

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